Valuing the patient experience in HTAs (and healthcare delivery assessments): going beyond QALYs

Professor Mandy Ryan

Health Economics Research Unit, University of Aberdeen

HERU is supported by the Chief Scientist Office of the Scottish Government Health Directorates and the University of Aberdeen.The author accepts full responsibility for this talk.

Structure

- Background – valuation in (health) economics
- Valuing the Patient Experience Project
  - The importance of going beyond QALYs
  - Valuation methods for going beyond QALYs
    - Group Work
- Concluding thoughts/reflections…. And discussion…

Background

- Limited resources - opportunity cost!
- Costs and benefits must be compared
- Valuing Benefit (estimating a quantifiable estimate of worth (QEW)) - one of greatest challenges facing economists

Valuation in Health Economics

- **Pre 1970 - cost-benefit analysis (CBA)**
  - willingness to pay (WTP) – through contingent valuation
- **1970s - cost-effectiveness analysis (CEA)**
  - e.g. cost per life year
- **1980s - cost-utility analysis (CUA)**
  - **e.g. cost per Quality Adjusted Life Years (QALYs) – HEALTH MAXIMISATION!**
    - **Standard gamble or time trade off**
- **1990s - cost-benefit analysis (CBA)**
  - Costs and benefits both measured in monetary terms
  - health and patient experience factors
  - Challenge of valuation
    - contingent valuation and discrete choice experiments (DCEs)
- **2000 forward**
  - QALYs dominate at policy level (NICE, SMC)
  - valuing patient experience factors important

HERU
HEALTH ECONOMICS RESEARCH UNIT

Quality Adjusted Life Years

Concerned with both *quantity* and *quality* of life

Increase in years of life = 10

Quality/utility weight = 0.85

scale 0-1, 0=dead; 1=perfect health

QALYs = 10 x 0.85 = 8.5

QALY framework

- H(Q) is measured on a scale whereby death and full health are assigned values of 0 to 1 respectively
  - Standard gamble – probability level of indifference
  - Time trade-off – trade time (years at end of life willing to give up)

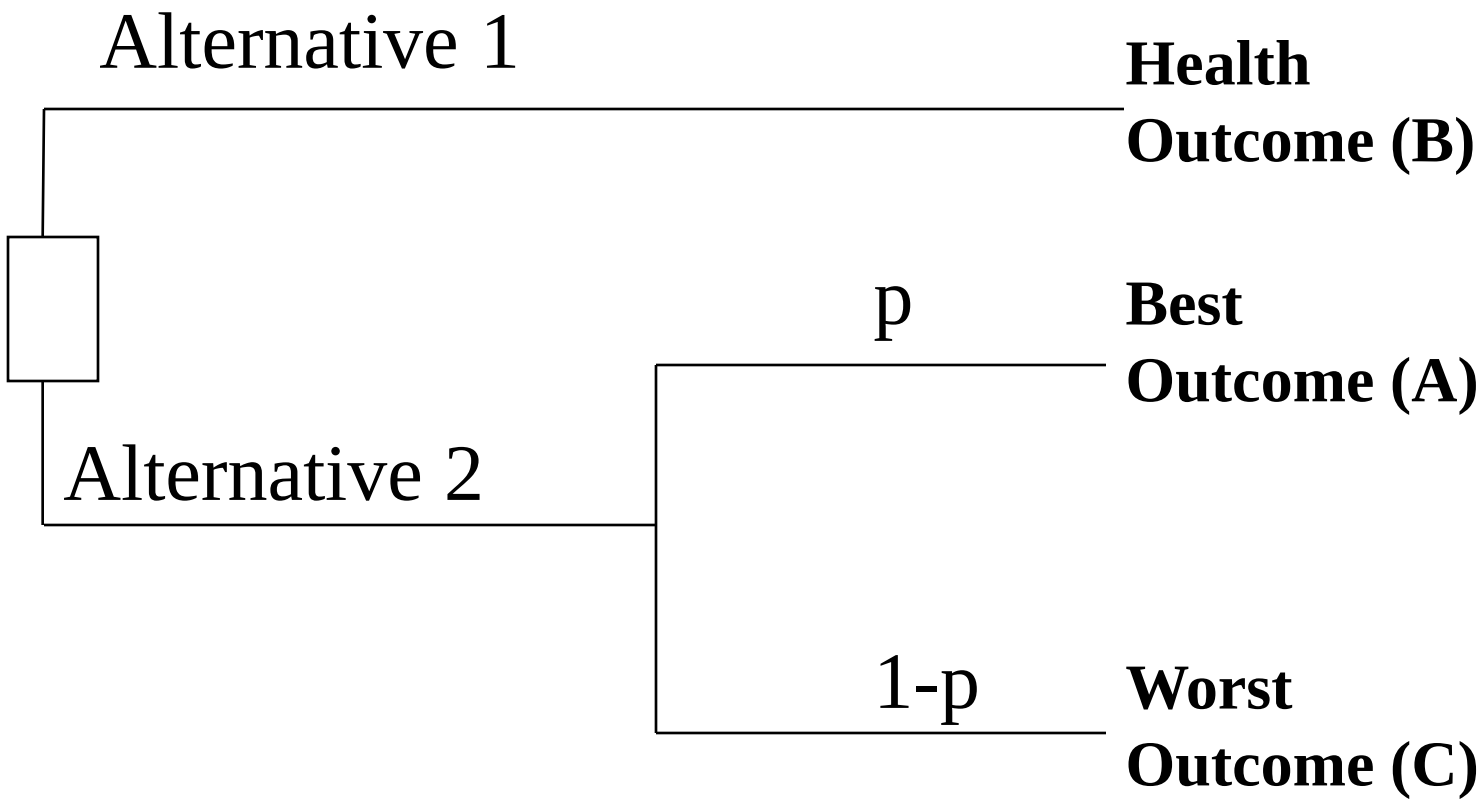
Standard Gamble

- Individual chooses between a certain outcome (B) or a gamble which may result in either a better outcome (A) than B (with probability P) or a worse outcome (C) (with probability 1-p).

- P* = level at which indifferent between certain outcome and gamble

- P* = quality weight

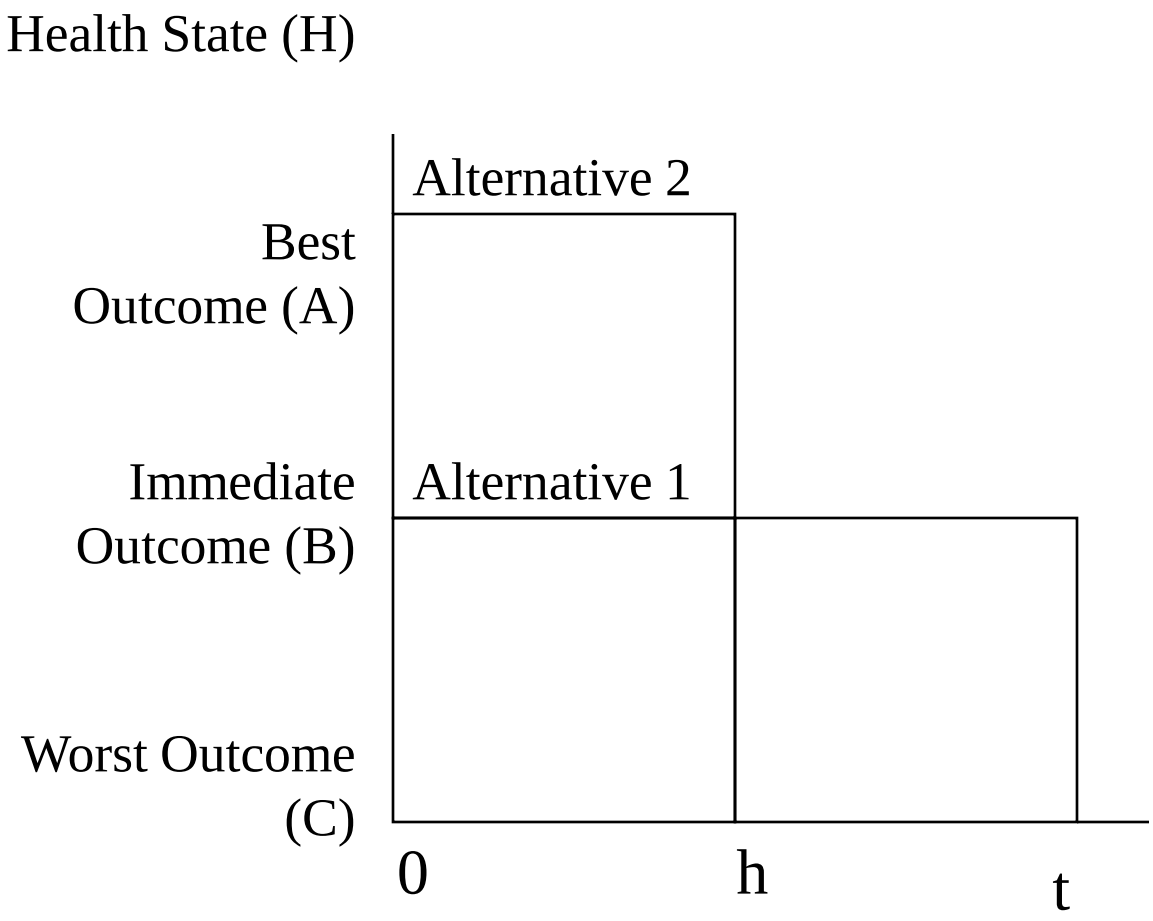
Standard Gamble



Time trade off

- Individual is presented with a choice between living for a period t in a specified but less than perfect state (outcome B) versus having a healthier life (outcome A) for a time period h (where h<t).
- h varied until respondent indifferent between outcome A and B
- h/t = quality weight

Time trade off



Valuation in Health Economics

- **Pre 1970 - <u>cost-benefit analysis (CBA)</u>**
  - willingness to pay (WTP) – through contingent valuation
- **1970s - <u>cost-effectiveness analysis (CEA)</u>**
  - e.g. cost per life year
- **1980s - <u>cost-utility analysis (CUA)</u>**
  - e.g. cost per Quality Adjusted Life Years (QALYs) – HEALTH MAXIMISATION!
    - Standard gamble or time trade off
- **1990s - <u>cost-benefit analysis (CBA)</u>**
  - Costs and benefits both measured in monetary terms
  - health and patient experience factors
  - Challenge of valuation
    - contingent valuation and discrete choice experiments (DCEs)
- **2000 forward**
  - **<u>QALYs dominate at policy level (NICE, SMC)</u>**
  - valuing patient experience factors important

HERU
HEALTH ECONOMICS RESEARCH UNIT

Valuation in Health Economics - House of commons health select committee review of NICE (January 2008)

- Time consuming
- Questions thresholds
  - Empirical work looking at WTP for QALY
- Criticises information used

- **'The law must be changed to allow NICE to take account of wider benefits to society…..'**

Yet…… NICE recent guidance (June 2008)

‘…. Cost-effectiveness (specifically cost-utility) analysis is the preferred form of economic evaluation…… Health effects should be expressed in terms of QALYs. …….

The focus on cost-effectiveness analysis is justified by the more extensive use and publication of these methods compared with cost-benefit analysis and the focus of the Institute on maximising health gains….’

Valuation in Health Economics

- **Pre 1970 - <u>cost-benefit analysis (CBA)</u>**
  - willingness to pay (WTP) – through contingent valuation
- **1970s - <u>cost-effectiveness analysis (CEA)</u>**
  - e.g. cost per life year
- **1980s - <u>cost-utility analysis (CUA)</u>**
  - e.g. cost per Quality Adjusted Life Years (QALYs) – HEALTH MAXIMISATION!
    - Standard gamble or time trade off
- **1990s - <u>cost-benefit analysis (CBA)</u>**
  - Costs and benefits both measured in monetary terms
  - health and patient experience factors
  - Challenge of valuation
    - contingent valuation and discrete choice experiments (DCEs)
- **2000 forward**
  - QALYs dominate at policy level (NICE, SMC)
  - **<u>valuing patient experience factors important</u>**

HERU
HEALTH ECONOMICS RESEARCH UNIT

UK MRC Methodology Panel (early 2008) - Valuing the Patient Experience

- **Importance of patient experience factors**
  - **Quality outcome measures/frameworks in England/Wales and Scotland**
  - **Increasing literature in health services research (including health economics)**

- National Institute for Health Research (NIHR) commissioned research:
  - What is meant by patient experiences
  - How to value patient experiences
    - We will come back to this…

Michael Parkinson, Ambassador for Government's Dignity in Care Campaign

- said there was a danger that carers did not see a "person who had lived a life, a worthwhile person, but a piece of decrepit and useless flesh".

  - Patients can't reach the food
  - When they ring the bell to get help with going to the toilet they are left lying in their own urine

Mid Staffordshire NHS Trust....

- Routine neglect
  - Patients left in soiled sheets which relatives were forced to wash
  - Patients left alone, leading to falls (not reported)
  - Problems getting food and drink
  - Government Report: ‘criticised the ineffective management which was too often concerned with hitting targets, particularly in A&E, as well as the lack of compassion and uncaring attitude of staff’

Patients' judgements on being ill and being rare (Huyard, 2009)

- '*The participants strongly expressed an aspiration to feel morally well-treated as a patient, which includes the feeling of being listened to, of being taken seriously, and of being supported and informed according to one's needs. In this regard, the disease experience presented here suggests that better fulfilling these expectations would greatly improve the subjective situation of patients with a rare disease.*'

UK MRC Methodology Panel (early 2008) - Valuing the Patient Experience

- Importance of patient experience factors
  - Quality outcome measures/frameworks in England/Wales and Scotland
  - Increasing literature in health services research (including health economics)

- **National Institute for Health Research (NIHR) commissioned research:**
  - **What is meant by patient experiences**
  - **How to value patient experiences**
    - **We will come back to this…**

‘Valuing Patient Experiences’ project

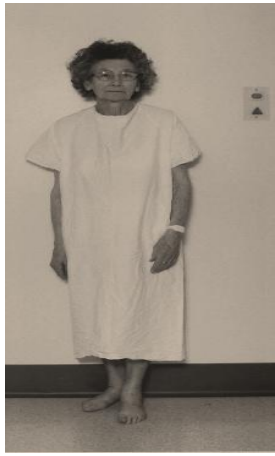
Background

- Project commissioned by National Institute Health Research (NIHR), UK
- Resource allocation decisions may not adequately reflect what matters to people about healthcare other than health
- Techniques for valuing aspects of healthcare experience (beyond health) not well developed

Project aims

- Stage 1:
  - To identify and characterise the aspects of healthcare experience that matter to people
  - To develop a ‘conceptual map’ to facilitate consideration/discussion of these
- Stage 2:
  - To review techniques for generating quantitative estimates of the worth (QEW) of the aspects of healthcare experience that matter

Stage 1: What aspects of healthcare experience matter to people, and why?



Two main activities:

‘Bottom up’

- Review of studies of what matters about healthcare experience

‘Top down’

- Look at ‘frameworks’ and theories that might help organise our thinking about what matters

‘Bottom up’ review

Possible organising frameworks?

- Healthcare quality

  e.g. Institute of Medicine, WHO ‘Responsiveness’

- Healthcare experience

  e.g. Mike Nolan’s ‘Senses’ framework

- ‘Overall’ wellbeing

  e.g. Carol Ryff’s ‘Subjective wellbeing’

Two key ideas...

... One overarching aspirational statement:

Healthcare enables me
to live a good life,
supporting my capabilities
to flourish as a human being.

Ambition for conceptual map

- Aiming for broad relevance, *but*
- Recognising that 'what matters' can vary

  (people have diverse health issues, social/cultural backgrounds, personal concerns and interests… and services have different aims and constraints)

A 'generic' starter map,

that summarises aspects of experience

that most people will recognise as important,

that has with enough detail to be meaningful,

but leaves scope for more detailed specification.

Open for discussion and revision.

"Healthcare enables me to live a good life, supporting my capability to flourish as a human being"

Healthcare staff

(supported by the teams and organisations in which they work)

Health care enables me to

Are **available** and **approachable**

Are responsive to changes in my health status

Attend to my (changing) health issues promptly and competently

(Really) listen

Show interest to **me**, to **my concerns** about **my health and care**, and **how these affect my life**

Take me seriously

Enable me to open up

Are attentive

Do not ignore my distress

Care about me as well as for me

Are **knowledgeable** and **competent**

about health, healthcare, disability, cultural diversity

Appreciate my anxieties and concerns

Are mindful of how I feel and responsive to my feelings

Understand me

Invite, welcome and answer questions

Recognise that how they do **their job** has implications for **my life**

Believe me, trust me

(unless have good grounds not to)

dedicated

Are motivated to help and enable me

generous

Relate to me *as a person*

Understand the bigger picture of my life

Promote continuity of carer

Form, sustain and provide appropriate endings for care relationships

Recognise their limits, help me get help from others if needed

Work *with* me not just *on* my health

Explain

My health issues, my healthcare options, how the system works

Are **consistent, predictable, reliable**

in providing care, information, advice, respect

Enable me to work with them and for myself

Discuss

my goals and priorities for my care

Keep me informed

Negotiate and allow me to influence priorities and **responsibilities** in my care

Show

Guide

Help me understand

Teach

Are responsive to my individual needs

Are appropriately flexible

(Apply practice guidelines and work to targets with discretion and sensitivity)

sincere

honest

Have **integrity**

genuine

Facilitate

Recognise and support my capacity for self care

Give me appropriate time

to discuss, consider, try

Encourage

Involve me

in decisions about my care

kind

empathetic

tolerant

Are **humane**

caring

patient

Do not demean or patronise me in our interactions

Do not abuse their power

Do not rely on or exploit my vulnerability

Treat me fairly in relation to others

Nurture and respect my capabilities

Allocate resources in line with need and without inappropriate discrimination

Are just

Do not judge me inappropriately

Do not treat me according to stereotype

(for health problems that threaten my survival[1])

Get the help I need

(for health problems that threaten my ability to flourish)

Feel secure

Be and feel safe as I use health services

My vulnerabilities are understood and not exploited

Cope

Enjoy life

Live well with health problems that cannot be fully cured or removed

Hope

Feel welcome and cared for as I use health services

Feel comfortable as I use health services

In a good environment

Among people who care

Be or become who I am and want to be

Support/maintain/ develop my own identity

(especially if this is threatened by illness or injury)

Feel I am not alone, not abandoned

Maintain dignity and self respect

Feel valued, accepted and respected as I use health services

Not inappropriately judged

Review, develop and adhere to my own values

in deciding about healthcare and living my life

Feel I matter

Trust and feel trusted[2]

Feel good about myself

Sustain and develop justified, positive, self evaluations

Sense of self-worth

self-respect

Sustain and develop good relationships

with health care staff, with family and friends, with community

Understand and be understood

Have a say

Partner with health professionals

Take acceptable risks

Negotiate, accept and exercise appropriate responsibility

Be involved in (decisions about) my care

Contribute to my care

Be prepared

Develop my capabilities

Feel enabled

Feel encouraged

Help address my own health issues

Participate in health care improvement

Engage in meaningful activity

Perform valued social roles

Stage 2 - Generating Quantifiable Estimates of Worth for Patient Experiences

- Best Worst Scaling
- Conjoint Analysis – ranking
- Conjoint Analysis – rating
- Discrete choice experiments
- Willingness to pay/contingent valuation
- Person Trade-off
- Standard Gamble*
- Time Trade Off*

* Used to estimate quality weights within QALY framework

- Budget Pie/Allocation of Points
- Swing weighting

Group Work

Your views on the acceptability of the different approaches identified for generating a quantifiable estimate of worth

Concluding thoughts

- Incorporating patient experiences into the economic evaluation– challenges for valuation?

- Incorporating patient experiences into the economic evaluation– would it make a difference?